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J. ARTHUR TRUDEAU: PIONEER IN MENTAL RETARDATION

As members of a club which has actively concerned itself with the problem of mental retardation in this State, I know the name of J. Arthur Trudeau is well-known to all of you.

Tomorrow marks six months since the sudden death of this great humanitarian. For me his passing meant the end of a long personal friendship and the loss of a powerful and esteemed colleague in the fight against mental retardation. For Rhode Island and the Nation his death meant the passing of one of those rare men who build upon personal tragedy a lifetime of service and dedication to their fellows.

Tonight, on the eve of this solemn anniversary I hope we may together recall some of the accomplishments of J. Arthur Trudeau and also look briefly at some of the major Federal programs in the field of mental retardation. Many of these programs have their roots in Arthur's pioneering efforts to arouse the public to the plight of the mentally retarded.

It was the birth of his own mentally retarded son in 1939 that set J. Arthur Trudeau on a lifelong crusade to bring understanding and hope to the mentally retarded.

In 1939, mental retardation was no less of a national problem than it is today. Yet virtually nothing was known about it, and there were few who were trying to learn. Usually no distinction was made between mental deficiency and mental illness.

In too many instances, the mentally retarded, especially those who were dependent adults, were closeted away as the secret shame of their families. Little mention was made of them in the family circle, once the doctor had made his final pronouncement that nothing could be done. The mentally retarded child, if he had a kind family, could at best expect sympathy and good maintenance care. But neither true understanding of his problem nor scientific help to aid him to become a productive member of society was available.

The less fortunate mentally retarded child or adult was placed in a public institution and received much of the same harsh treatment as was then often accorded the mentally ill. By the middle 1930's studies of eugenics were interpreted to prove the potential danger to society of mental retardates. These studies caused more than half the states to adopt compulsory sterilization laws designed to prevent retardation in succeeding generations.

That those laws which still exist are seldom enforced is a credit to our collective good sense. It is now widely believed that sterilization is highly unlikely to appreciably reduce the numbers of mentally retarded in future generations. Some retardation is inherited, but other forms result from infectious disease, brain injury, and social deprivation. Retardation occurs in families at all social and economic levels and may not be present at birth.

It was thus a hostile world J. Arthur Trudeau faced when he began his long drive for understanding and help for his son and for the other mentally retarded children of this country.

After trying in vain to find help for his son, J. Arthur Trudeau helped found the Parent's Council for Retarded Children in 1951. He was chairman of the Association's first fund drive and served as the group's president from 1955 to 1957.

I vividly recall one evening in 1954 when I attended a meeting of some parents of retarded children at Arthur's invitation. Although at that time I had been active in the field of health legislation for some time and was quite familiar with most of our nation's great health problems, I must confess I was very much in the dark about the scope and consequences of mental retardation.

That meeting served to open my eyes to a problem that we now know to be the number-one affliction among children. Only mental illness, heart disease, arthritis, and cancer have a higher prevalence in our total population, and these tend to come late in life, while mental retardation comes early.

Yet in 1954 not a single Federal dollar was being spent on research in this field. Most facilities for long-term care of the mentally retarded were pitifully sub-standard, and qualified medical and technical personnel in the field, woefully scarce. Welfare assistance for families with retarded children was similarly inadequate.

Even those families who could well afford to sustain expensive long-term medical care found the situation hopeless. Mrs. Sargent Shriver, sister of President Kennedy, recalled in a magazine article two years ago that two decades previously, when her family sought help for her retarded sister Rosemary, they found little but "cynical despair."

"Even 10 years ago," she reminded us, "not a single university was focusing on mental retardation. Scientists cared little about it, doctors regarded it as hopeless, the public confused it with mental illness."

I left that meeting back in 1954 deeply shocked, yet at the same time encouraged by the optimism of those brave parents who refused to believe the doleful pronouncements that nothing could be done.

I brought the story of that meeting back to Washington and I soon found that very few people were aware of the scope and depth of the problem of mental retardation. Once all the facts were brought to light however, I am glad to say, Congress responded in 1956 with the first Federal appropriation -- \$750,000 -- for research in mental retardation. This is a relatively small amount by today's standards, but certainly enough to start things moving.

The confidence of those courageous parents I met ten years ago has been magnificently borne out. Progress in meeting the medical and social needs of the mentally retarded has been gratifying indeed.

Yet a true crusader is never satisfied until nothing less than ultimate victory is attained. Despite the great strides taken toward the conquest of mental retardation in the past decade, J. Arthur Trudeau never relented in his efforts to, in his words, "help my boy Kenny, number one; and to help other kids, number two."

Arthur was elected a director for the northeast region of the National Association for Retarded Children in 1957 and the following year was named to the Advisory Commission for Ladd School. In 1962 his unceasing work led to his nomination for a leadership award of the Joseph P. Kennedy, Jr. Foundation.

Arthur paid a great honor to me in his work to incorporate the John E. Fogarty Foundation for the mentally retarded. The Foundation was an outgrowth of the work he began in 1962 as chairman of occupational training at the Center which also, thanks to the generosity and good will of the people of Rhode Island, bears my name.

In April 1965, Governor Chafee appointed J. Arthur Trudeau to a 12-member advisory council on mental retardation to study the needs for comprehensive community programs in the State. And, a year ago this month, Arthur was appointed to a three-year term to the state Advisory Council on Mental Retardation. That J. Arthur Trudeau did not live to complete this term is our immeasurable loss.

Nor did he live to see the completion of the community center for retarded children in Apponaug. When that center is completed, it will serve as a fitting memorial to one who worked tirelessly to raise funds for its construction.

Yet he would have been grateful in the further knowledge that the State of Rhode Island has at last decided to lend its support to the center.

The awareness that J. Arthur Trudeau helped to create in the field of mental retardation spread beyond the borders of this State. His pioneering efforts played a major role in shaping the comprehensive Federal mental retardation program we have today.

I have been privileged to be one of the architects of this Federal program which includes preventive services designed to reduce the incidence of mental retardation. Maternity and Infant Care projects provide health care to prospective mothers in high risk populations. Nearly thirty such projects have been approved. Grants also support screening programs for phenylketonuria (PKU) and other metabolic disorders which lead to mental retardation. As of September, 1965, thirty-two States had enacted laws concerning PKU, most of them making screening of this disorder mandatory.

Other programs are administered through the States to increase the health and welfare services available to the retarded. These programs are helping to enlarge existing mental retardation clinics by adding staff, increase the number of clinics, and begin evaluations of children in institutions. State agencies, with the help of Federal funds are extending screening programs, providing

treatment services for physically handicapped retarded youngsters, increasing inservice training opportunities, and providing homemaker and other care services for the mentally retarded.

The mentally retarded receive a variety of services through programs supported by the Vocational Rehabilitation Administration. These services include diagnosis, physical restoration, counseling and testing, and assistance in job placement and follow-up to insure successful rehabilitation. The Vocational Rehabilitation Act Amendments of 1965 will assist in the rehabilitation of additional mentally retarded persons to productive lives.

Projects supported by the Public Health Service include new techniques of providing services to the mentally retarded such as new referral methods, new methods of care and management of the retarded, and improved methods of care, treatment, and rehabilitation. Major emphasis is being given to projects which will result in the provision of the array of services needed for comprehensive and continuing care.

The Elementary and Secondary Education Act of 1965 provides the opportunity for school districts to develop creative educational programs for the mentally retarded.

Training programs for professionals who work with the mentally retarded are a part of many of the service programs. These include professional preparation for research in the biological, medical and behavioral sciences. Training grants help supply personnel



for the provision of health, social, and rehabilitative services for the mentally retarded. Other grants help to train teachers and other educational personnel in the special education techniques necessary to the teaching of the mentally retarded. Presently close to 5,000 teachers are in training for teaching the mentally retarded and other handicapped children.

The Social Security Amendments of 1965, which included Medicare in its provisions, also vastly increased the Department of Health, Education, and Welfare's program for training professional personnel who work with the mentally retarded. New authority included in these amendments will make possible the training of a variety of additional personnel through grants to institutions of higher learning.

Approximately \$34 million was devoted in fiscal year 1966 to research supported by the Public Health Service related to mental retardation. Grants from the Office of Education support research and demonstration projects in the area of education and projects related to the adaption of communications media to educational problems of the mentally retarded. The Vocational Rehabilitation Administration supports research projects that seek to coordinate community resources for the mentally retarded.

Funds are awarded by the Department for construction of three types of facilities for the mentally retarded. The Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 provides for the construction of research centers to assist in the development of new knowledge for preventing and combating mental retardation, university affiliated facilities for the mentally retarded to provide for training of physicians and other professional personnel, and community facilities for the mentally retarded to provide diagnosis, treatment, education, and training including sheltered workshops.

Amendments to this Construction Act passed last year added funds for the initial staff and operation of these facilities, extended and increased appropriations for research and demonstration projects to improve education of retarded children, and authorized increased annual sums through fiscal year 1969 for training teachers of the retarded.

The Welfare Administration administers a public assistance program to aid needy families to support retarded children who are permanently and totally disabled.

In all, a total of 48 programs provide financial assistance for service programs, research and demonstration projects, training, construction, income maintenance, and other assistance programs in the Department of Health, Education, and Welfare.

To coordinate these activities a Secretary's Committee on Mental Retardation has been formed. Representatives serve on this Committee from each unit of the Department that has a mental retardation program. Mental retardation activities are thus administered as a unified, whole program which has as its objective combating mental retardation with every resource at our disposal. The Committee also keeps in close touch with groups outside the Federal Government concerned with mental retardation programs.

The development of this wide array of service and assistance programs on the Federal level was very gratifying for J. Arthur Trudeau. Yet I know that deep inside he regretted that they did not occur thirty years sooner so that his own son, who is rightfully any father's chief concern, might have been helped. Still I know he was deeply grateful knowing that, at last, many children of succeeding generations might be spared the tragedy of mental retardation.

He also knew that much work still remains to be done. Great gaps still exist in our knowledge of mental retardation. For example, Arthur's son Kenny is one of the 75 per cent of the mentally retarded for whom no cause of their affliction is known. More personnel need to be trained. Many more centers such as the Trudeau Memorial Center, to which this club has given its full support, must be established throughout the Nation.

I can promise that we in Congress will see that adequate funds are made available, but under our Federal partnership system the States must supply the initiative for employing these funds for useful purposes. I am sorry to say that many States have been slow in taking advantage of the assistance available to them.

It is here that service clubs such as Rotary render an invaluable service. By creating public awareness, and through your fund-raising activities to get the Trudeau Center built, your club and others have shown that the people of this State wanted and would support such a center. Such a demonstration was undoubtedly a major factor in securing State interest and assistance for the project.

I can only hope that the recent State action is only the first of many activities which Rhode Island will undertake to fight mental retardation. Rhode Island can develop a comprehensive program in this field that could serve as a model to other States.

Certainly J. Arthur Trudeau would be most pleased with this recent turn of events. But restless pioneer that he was, he would urge us on to new frontiers, to cut through new barriers of ignorance and apathy until the goal he sought for twenty-six years was finally achieved. No less than the final elimination of mental retardation on all its fronts would have satisfied him -- no less I am sure will satisfy us.